

EXPLORING DRY EYE THROUGH THE LENS OF NARRATIVE MEDICINE

Insights from a multicenter study.

BY EMANUELA ARAGONA, MD, PHD

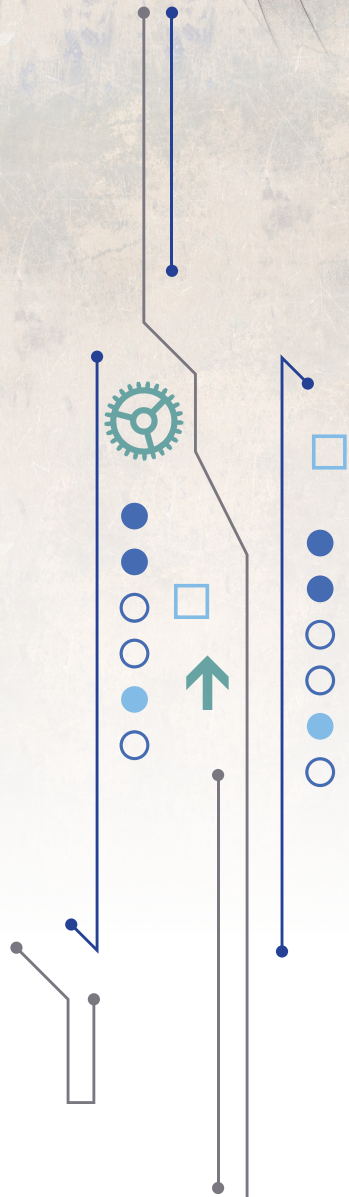
Interest in the patient experience of chronic conditions, including dry eye disease (DED), has grown. Standardized tools such as questionnaires can provide valuable quantitative data but often miss the nuances of how DED affects patients' daily lives. To bridge this gap, my colleagues and I conducted a narrative medicine study across 38 Italian centers that provided fresh insights into the lived experiences of patients with DED and their caregivers.

Narrative medicine—already established in fields such as oncology and neurology—offers a framework to examine the emotional, practical, and relational challenges faced by patients. By engaging 171 patients, 37 informal caregivers, and 81 ophthalmologists, our study provided a comprehensive look at the realities of living with DED.¹

KEY FINDINGS: BEYOND THE SURFACE OF SYMPTOMS

The practical challenges of DED such as difficulty viewing screens, driving, and managing environmental triggers are well documented. Our study highlighted several often-overlooked issues—frustration, fear, and a perception of decreased empathy and understanding from health care providers. One of our most compelling findings was a disconnect between how patients and caregivers perceive the burden of DED: although 19% of patients described their condition as disabling, 35% of caregivers classified it as such. This may suggest that caregivers often recognize the severity of challenges more acutely than patients themselves.

Our study also highlighted the economic burden of managing DED, particularly in countries such as Italy, where the cost of long-term treatment falls solely on patients. Managing a lifelong condition with artificial tears and antiinflammatory drops can impose a significant financial strain, which may compromise patients' adherence to prescribed therapy. This concern was echoed by patients and caregivers, both of whom expressed a need for greater systemic support, such as the inclusion of DED treatments within national health care frameworks.



STRENGTHENING THE THERAPEUTIC ALLIANCE

Ophthalmic surgeries, particularly anterior segment procedures, are often described as quick and straightforward. Although this reassurance can reduce patients' preoperative anxiety, it may inadvertently oversimplify the postoperative experience. Patients who experience symptoms such as burning, tearing, blurred vision, or dryness after surgery may feel frustrated or misunderstood if their expectations are not managed properly.

By setting realistic expectations, acknowledging potential ocular surface-related symptoms, and explaining the need for postoperative drops, surgeons can enhance patient satisfaction and trust. Patients

emphasized their desire to feel heard and understood.

IMPLEMENTING NARRATIVE TOOLS IN PRACTICE

Narrative medicine provides practical tools to strengthen communication with patients and identify gaps in their understanding. Open-ended questions such as "What are your hopes for this surgery?" and "What do you think the recovery process will involve?" can help surgeons uncover patient expectations and address misconceptions proactively.

This approach is particularly relevant for refractive and eyelid surgeries, where high expectations increase the risk of dissatisfaction. For example, refractive surgery patients are often young and unaware of long-term ocular surface risks, so they may benefit from a clear discussion of potential symptoms.

Similarly, patients undergoing eyelid surgery for aesthetic reasons must understand that dryness, foreign body sensation, and discomfort may arise postoperatively. Managing patient expectations preoperatively can prevent dissatisfaction and build trust.

The successful management of chronic diseases such as dry eye extends beyond clinical interventions. The emotional and practical realities of patients' lives must be considered in addition to medical treatment. ■

1. Aragona P, Barabino S, Akbas E, et al. Utilising narrative medicine to identify key factors affecting quality of life in dry eye disease: an Italian multicentre study. *Ophthalmol Ther*. 2024;13(11):2965-2984.

EMANUELA ARAGONA, MD, PHD

- Department of Ophthalmology, IRCCS San Raffaele Scientific Institute, Milan
- aragona.emanuela@hsr.it
- Financial disclosure: Research funding (Bausch + Lomb)